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Governor

State of Connecticut
Department of Developmental Services



Peter H. O'Meara
Commissioner

Kathryn du Pree
Deputy Commissioner

January 12, 2009

To: Public Health Committee members

From: Peter H. O'Meara, Commissioner

Re: Report on the results of the Pilot Autism Spectrum Disorders Program, pursuant to Section 37 of Public Act 06-188.

Pursuant to Section 37 of Public Act 06-188 (effective July 1, 2006), the Commissioner of Developmental Services, in consultation with the Commissioners of Social Services and Mental Health and Addiction Services and any other commissioner the Commissioner of Developmental Services deems appropriate, was charged with establishing a pilot autism spectrum disorders program, to provide a coordinated system of supports and services, including case management, for persons with autism spectrum disorders who do not have mental retardation, as defined in section 1-1g of the general statutes, and their families.

In addition, Public Act 06-188 requires the Commissioner of Developmental Services to report to the Public Health Committee by January 1, 2009 concerning the results of the Pilot. The report is to include recommendations concerning a system for addressing the needs of persons with autism spectrum disorder, including but not limited to, recommendations:

1. establishing an independent council to advise the Department of Developmental Services with respect to system design, implementation and quality enhancement,
2. establishing procedural safeguards,
3. designing and implementing a quality enhancement and improvement process, and
4. designing and implementing an interagency data and information management system

Background on the Establishment of the Pilot Autism Spectrum Disorders Program For Adults Who Do Not Also Have Mental Retardation:

The pilot program was established in the summer of 2006. A system of supports and services using a Medicaid waiver model was developed with the assistance of the steering committee. Eligibility criteria and a system to review applications were established. Eligibility determination is established through a review of personal, clinical, and educational records. Criteria for inclusion in the pilot is as follows:

- a. Diagnosis of an Autism Spectrum Disorder made through Psychological and/or Psychiatric Evaluation(s) that clearly outline the justifications for the differential diagnosis.
- b. Legal residency in the State of Connecticut (note that the pilot is only available in two geographic areas of the state at this time).
- c. Impairment prior to age 22 years.
- d. Impairment expected to continue indefinitely (chronic).
- e. Substantial functional limitations in three (3) or more of the following areas of major life activity: Self Care, Receptive and Expressive Language, Learning, Mobility, Self-Direction, Capacity for Independent Living and Economic Self-Sufficiency.
- f. Cognitive and adaptive functioning above the level of mental retardation (i.e. IQ equal to or greater than 70).
- g. At least 18 years of age and have exited from school services.
- h. If an individual has a co-morbid psychiatric disorder: The individual must possess a level of coping skills, reality testing, personality integration, and impulse control necessary to be able to take advantage of the services offered by the Autism Spectrum Disorder Adult Program. The individual must be receiving any psychiatric treatment needed for him/her to utilize the services offered by the Program. An applicant may be denied eligibility if the co-morbid psychiatric disorder predominates and is likely to render services which may be available through the Autism Spectrum Disorder Adult Program ineffective. (NOTE: "Co-morbidity" means a concomitant but unrelated pathological or disease process.) The individual would be able to re-apply at such time that the psychiatric disorder is stabilized.

A full-time case manager was hired for the pilot program. A request for applications for provider agencies was issued. There were six initial provider agencies that were approved to provide services. In addition, an agreement was entered into with the University of Connecticut Center on Aging to develop an outcome study on the entire pilot program. Results of this study were recently received and are currently being analyzed. The results will be shared under separate cover. A training video series was developed for staff of private provider agencies who are providing supports and services to pilot participants.

In August 2008, as the pilot was expanded into Hartford County, another case manager was hired. The pilot is currently funded through June 2009. At this time, there are 52 individuals enrolled in the pilot. Fifty of the individuals have individual services and supports in place as documented in their Individual Service Plan and in their individual budgets. Two individuals are newly enrolled and their plans are in the process of being developed.

The following is a list of services that are offered through the pilot program, with life skills coach, job coach and community mentor being the most utilized supports.

<i>Direct Services:</i>
Life Skills Coach
Job Coach
Community Mentor
Job Developer
Interpreter Services
Specialized Driver Assessment
In-home Respite
Out-of-home Respite
Personal Emergency Response System
<i>Consultative Services:</i>
Dietitian/Nutritionist
Speech Therapy
Occupational Therapy
Physical Therapy
Autism Spectrum Disorder Specialist
Recreation Therapist
Advanced Practice Registered Nurse (APRN)
Registered Nurse (RN)
Counseling
Behavior Management
Clinical Psychology

Recommendations Concerning A System For Addressing The Needs Of Persons With Autism Spectrum Disorder:

Technical Assistance Collaborative (TAC) is a national non-profit organization that works to achieve positive outcomes on behalf of people with disabilities, people who are homeless, and people with other special needs by providing state-of-the-art information, capacity building, and technical expertise to organizations and policymakers in the areas of mental health, substance abuse, human services, and affordable housing. DDS contracted with TAC to provide a Medicaid waiver feasibility study to address Medicaid funded services and supports to adults with autism spectrum disorders who do not also have mental retardation as well as to develop a Medicaid waiver application should there be approval to do so. All data was collected and analyzed. In June 2008, additional data pertaining to adults diagnosed with autism spectrum disorders receiving services from the Department Of Mental Health and Addiction Services Young Adult Services Program was collected. That data is currently being analyzed and will be added as a narrative to the Feasibility Study.

1) Establishing An Independent Council To Advise The Department Of Developmental Services With Respect To System Design, Implementation And Quality Enhancement:

A Steering Committee was established in March 2006. The 40-member steering committee was comprised of representatives of several state agencies, several parent advocacy groups, and professionals from the community. The steering committee was instrumental in the development of the pilot structure and processes. In January, the newly created Independent Advisory Council of the Division of Autism services formally adopted their bylaws. The bylaws are available on the DDS website. All of the members of the original steering committee were invited to this new group. The steering committee is no longer in existence. The current Independent Advisory Council has 28 members and meets every other month. The group is comprised of several representatives of state agencies, a member of the legislature, representatives of parent advocacy and support groups, community professionals, and a participant of the pilot. It is an active group with several working subcommittees.

2) Establishing Procedural Safeguards:

Procedural safeguards are a requirement of the federal Individuals with Disabilities Education Act (IDEA 2004) for students receiving special education services from their school district. Specifically, procedural safeguards are a system of recourse for parents who are in disagreement with decisions made at the local level (e.g. mediation, due process hearing, complaints, etc.). As this program is a pilot there are no procedural safeguards.

If, in the future, the pilot services and supports should be administered through a Medicaid waiver, Medicaid safeguards will be required and implemented and a fair hearing process would be established. DDS's Fair Hearing process for other Medicaid waiver services provides the opportunity to request a Fair Hearing under federal regulations (42 CFR §431), to individuals: (a) who are not given the choice of home and community-based waiver services as an alternative to institutional level of care specified for this waiver; (b) who are denied the service(s) of their choice or the provider(s) of their choice; or (c) whose services are denied, suspended, reduced or terminated.

3) Designing And Implementing A Quality Enhancement And Improvement Process:

For the purposes of the pilot, all individual service plans, individual budgets and review of outcome progress are reviewed by the Pilot Manager. Clinical review team meetings are held monthly. The purpose of the team is to review the progress of each individual and to make recommendations to the pilot program. Individuals participate on the team with their families and service providers as well as with the staff of the pilot and four clinical members of the Independent Advisory Council. Each Individual Service Plan and all outcome progress is reviewed along with the delivery of services to meet outcomes.

If, in the future, the pilot services and supports should be administered through a Medicaid waiver, the DDS Quality Management System will be adopted. DDS currently operates a formal, comprehensive system to ensure that the Medicaid waiver meets the quality assurances and other requirements contained in the waiver. Through an ongoing process of discovery, remediation and improvement, DDS assures the health and welfare of participants by monitoring: (a) level of care determinations; (b) individual plans and services delivery; (c) provider qualifications; (d) participant health and welfare; (e) financial oversight and (f) administrative oversight of the waiver. DDS further assures that all problems identified through its discovery processes are addressed in an appropriate and timely manner, consistent with the severity and nature of the problem. The quality review system is an automated system that documents and collects quality data. Specifically, the reviews pertaining to a family home or an individual's home would be adopted.

4) Designing And Implementing An Interagency Data And Information Management System:

There are currently no Information Technology staff assigned to the pilot program. There was a hiring freeze that was instituted in the spring of 2008. Should the pilot services and supports be administered through a Medicaid waiver in the future that also addresses the needs of individuals from the Department of Mental Health and Addiction Services or another state agency, the benefits of an interagency data and information management system versus the costs of such system will be assessed.

Please contact Kathryn Reddington, Autism Coordinator at (860) 418-6026 with any questions related to this report.